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Reframing Aboriginal Family Caregiving

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OVERVIEW

This chapter describes the experiences of caregiving for Aboriginal families living with a serious mental illness. It highlights the disconnection with mental health providers and their lack of knowledge of Aboriginal concepts of caregiving. Indeed, there is limited knowledge of the complexity of caregiving across the mental health sector. This chapter explores Aboriginal caregiving through multiple lenses. Firstly, through the global context for mental health and Aboriginal families; secondly, through stories of Aboriginal people's experiences of mental health and caregiving; and, thirdly, through coalescing these experiences into considerations for an Aboriginal model of caregiving. It argues that Aboriginal mental health needs to be understood within the context of colonisation. Most importantly the chapter draws on the stories of Aboriginal people and their experiences of caregiving for those living with a serious mental illness to assist mental health practitioners and those working in the social services to gain a greater understanding in order to enhance their practice.

INTRODUCTION

This chapter is based on a research study that describes Aboriginal people's caregiving experiences. Many of the Aboriginal families found the attitudes of health professionals in hospitals to be patronising towards Aboriginal people, and generally lacking any commitment to collaborate with patients and their families.

A critical point in my own professional journey in the mental health services occurred when a keynote speaker living with a serious mental illness delivered an eloquent and powerful presentation at a conference in Sydney in 2005. This extraordinary young woman spoke not as someone living with a serious mental illness, but as a person with an authoritative message of caregiving and mental illness. Her address to the mental health professionals was inspiring and transformational; describing a vision of caregiving where Aboriginal families living with a serious mental illness can have greater control over their own futures.

MENTAL HEALTH AND CAREGIVING – THE CONTEXT

Mental Health Disorders – A Changing Scenario

It is estimated that world-wide there are currently 450 million people living with a psychiatric or behavioural illness, with a future prediction of at least one-in-four developing a psychiatric or behavioural illness in their lifetime. The morbidity and mortality impact on communities is considerable, with five of the ten significant listed disabilities resulting from a mental illness, and causes of premature deaths primarily due to a psychiatric condition.[1] There is increasing evidence linking poor mental health outcomes to negative social and economic situations as discussed in Chapter 6 (Zubrick and colleagues). Most at risk are vulnerable groups, including people with disabilities (both mental and physical), and Indigenous populations and refugees, who are often marginalised socially and economically from society.[2]

In the 1950s throughout the Western world, there was a shift in the treatment of mental illness with the introduction of deinstitutionalisation, which involved releasing people with a mental illness from secure institutions and mental hospitals back into the community. The implementation of this policy in mental health has had a major impact on every aspect of community life.

Until the change to deinstitutionalisation in Australia, the state assumed the carer role when a family was unable to care for a family member.[3] Since the 1950s, there has been greater involvement by consumers and their caregivers in the processes of treatment and care for people living with a serious mental illness. In recent times the formalising of consumer and carer networks has improved the situation to some degree.[4] However, the emergence of the professional care approach has diffused the issue, with the result of hybrids or new forms of mixed care arrangements.[5] These continued shifts within mental health in the care paradigm have had varied results for all families.

Mental Health Services and Aboriginal People

In Australia, Aboriginal and Torres Strait Islander peoples have, over a long history of colonisation, experienced intergenerational racism and structural discrimination, which continues to have a negative impact upon individuals, families and communities.[6] (See the discussion by Dudgeon and colleagues in Chapter 1.) The Third National Conference on Human Rights and Mental Health held on 8 and 9 September 2005 in Canberra found that cultural prejudice still exists in Australia in the 21st century. The conference report stated as one of its four findings that:

> *Many Australians experience discrimination through the governmental, penal, legal and health systems because of their mental health, race, skin colour, sexuality, sexual formation and refugee status.*[7]

Past policies and practices directed at Aboriginal and Torres Strait Islander peoples have resulted in a form of cultural genocide, including dispossession and removal from traditional lands and the forced removal of children.[6,8] These acts have all constituted abuses of human rights and have left a legacy of contemporary trauma and unresolved loss and grief and the need for individual, family and community healing as outlined in Chapters 17, 24, 25, 27, 28 and 29.

Aboriginal and Torres Strait Islander peoples in Australia experience disproportionate poor health consequences in contemporary society.[9] A major contentious issue has been the inadequacy of mainstream mental health services to respond appropriately to the mental health needs of Aboriginal people.[10] Aboriginal people experience a double-bind situation whereby they live with both the stigma of a mental illness and racism because of their Aboriginality.[11-13]

Australian Government Policy Responses

There have been a number of high-level reports, strategies and policies on mental health in Australia highlighting the deficiencies in both access and response to the needs of Aboriginal and Torres Strait Islander peoples living with serious mental illness. These include the National Mental Health Commission (NMHC) 2012;[10] National Mental Health Consumer and Carer Forum 2011;[14] Mental Health Council of Australia 2012, 2009.[15,16] The Recognition and Respect-Mental Health Carers Report 2012[15] produced by the Mental Health Council of Australia, showed that there are still significant issues that need to be addressed, the most pressing being the appropriateness and adequacy of the provision of mental health services to the general community.[15] This is even more so for Aboriginal people and their caregivers, where the Mental Health Council of Australia, Adversity to Advocacy 2009[16] report and the National Mental Health Commission 2012[10] report card describes the provision of mental health services as being both inadequate and inappropriate and recommend that changes be implemented immediately.[10,16] See Chapter 5 (Zubrick and colleagues) for a more detailed discussion of the key commissions, reports and initiatives that have impacted upon Aboriginal mental health and social and emotional wellbeing and ultimately influenced a broader appreciation of the role of carers, families and communities in addressing Aboriginal mental illness.

Caregiving: Being Present and Being Human

There is an urgent need to acknowledge and support the important role carers play within the mental health system. The renowned medical anthropologist and psychiatrist Professor Arthur Kleinman was, for seven years, the primary caregiver for his wife who was diagnosed with a debilitating form of Alzheimer's disease. Kleinman[17] provides a moving and eloquent, but also distressing, and at times harrowing, account of his experiences of being a primary caregiver for his wife:

> *Caregivers protect the vulnerable and dependent. To use the experience-distorting technical language; they offer cognitive, behavioural, and emotional support. And because caregiving is so tiring, and emotionally draining, effective caregiving requires that caregivers themselves receive practical and emotional support. But, to use the close experiential language of actually doing it, caregiving is also a defining moral practice. It is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the carereceivers, more present and thereby fully human.*[17(p293)]

In a society that benefits certain groups, particularly academics and medical professionals, with their attendant privileges of power, authority and control, it is easy to forget our humanness with all its frailty, fragility and vulnerability. Indeed, unless we directly experience either living with, or indirectly caring for, someone living with a debilitating chronic condition, we can forget our human condition or what it means to be fully human. As Kleinman states, the act of caregiving can often propel us into a virtual unknown:

> *Caregiving is not easy. It consumes time, energy and financial resources. It sucks out strength and determination. It turns simple ideas of efficacy and hope into big question marks. It can amplify anguish and desperation. It can divide the self. It can bring out family conflicts. It can separate out those who care from those who can't or won't handle it. It is very difficult. It is also far more complex, uncertain, and unbounded than professional medical and nursing models suggest.* [17(p293)]

Personal stories offer much for us to consider as people, practitioners, professionals or students in one of the caring professions. Hopefully, sharing Kleinman's experiences of caregiving, and those of the many Aboriginal families who shared their stories in my study, will enable mental health practitioners and students to come closer to their own unique experiences of being human, and of being both fragile and vulnerable. In our acceptance of our own humanness, we are more able to view others with greater compassion and understanding in our professional and everyday practice.

Drawing on those stories of Aboriginal people and their experiences of caregiving for those living with a serious mental illness, this next section discusses the findings from my study. Very little is understood about what constitutes caregiving for Aboriginal people living with a severe mental illness. The caregiver's stories are often a mixture of both joy and tragedy. Their stories are important because they provide a view into the lives of caregivers and of their discoveries in their journey of understanding of mental health from a deeply personal perspective.

MENTAL HEALTH AND CAREGIVING – AN ABORIGINAL EXPERIENCE

A Dark Place – Challenges of Living with a Serious Mental Illness

The stories of Aboriginal caregivers living with a serious mental illness highlight and confirm the multiplicity of effects of cultural racism, stigma and discrimination, as well as institutional and individual blocks to them providing care for their family members.[18] In general, the major focus and preoccupation of people living with a serious mental illness and their caregivers were issues surrounding mental illness itself. The chronic nature of mental illness makes the reality of day-to-day living difficult. For example, Andrea, an Aboriginal woman in the study, described living with a serious mental illness as living in a dark, scary place:

> “ *It is a dark place, and the main thing of coping with it is to know that you've got the support there, even though half the time when you're in a mental state you don't think there is. You know, and it takes a lot, takes a lot out of you because it's one scary place. That's all I can say; it's really scary.*[19] ”

Most of the Aboriginal people in the study, either those living with a serious mental illness or those caring for them, talked about their sense of powerlessness when mental illness descended into their lives. Gail, a caregiver described her daughter's behaviour as bizarre and totally out of character, leaving her both confused and bewildered as to what to do:

> “ *It was at that point that I recognised that it was beyond the realms of my capacity to be able to deal with, or make sense of, what was happening. And I thought, 'This is really bizarre, this is beyond my control, this is something I don't have a grip on. What the hell is going on here!' I actually thought I was perhaps losing my mind.*[19] ”

Ellen's grand-daughter, Andrea, acknowledged the importance of the support of her grandmother in her recovery:

> “ *It was really scary for everyone. It was like they all stood down from it and it was more like Nana just stood up and it's like, 'Well we're either going to be here to help, or otherwise we're just going to stand back and bicker amongst each other and nothing's going to get done'. They were scared because they didn't know what was going on. And it took for Nana to stand up and say, 'No, now is the time that we stand together, so who's going to stand with me'. It took a while but they all stood up in the end.*[19] ”

The Important Role of Families

Mental illness can be a long-term, recurrent or persistent condition. Aboriginal families have shown that, even though they lack physical resources, they do not lack emotional resources when responding to chronic illness. They show remarkable resilience, compassion and insight when confronted with difficult life situations.

The Aboriginal kinship system can provide considerable support through the immediate and extended family networks. The extended family network and their involvement and support can be very important for those involved in caring for Aboriginal people living with a serious mental illness.[6] This support may go unnoticed and as a result be under-utilised by mainstream mental health providers. On the other hand, there is a risk that mental health practitioners may exploit these resources, so measures need to be in place to ensure that this does not occur. Meaningful partnerships between families and mental health providers are essential in the recovery process of someone living with a serious mental health illness.[8]

Cathy spoke of the difficulties she experienced with mental health services and drug and alcohol agencies, which resulted in a crisis for her son:

> “*That was a relief that he was diagnosed ... I know a lot about mental illness and I knew he had symptoms of schizophrenia and what I found unhelpful was when I called the Psychiatric Emergency Team, and I'm not criticising the Psychiatric Emergency Team, but being told it is not a mental illness. I understand the system, I work in the system, so I can see it from both perspectives. But when you're told that it's a drug issue and it's like, I know you can only assess someone's mental state if they're straight ... I found that frustrating, really frustrating. I think it's because of the stigma related to drug psychosis.*[19] ”

Cathy's experience also highlights the failure of the system to deal with comorbidities of drugs and mental illness and the associated issues of dual diagnosis discussed in Chapter 8 (Wilkes and colleagues).

Caregiving in a Family Context

Most Aboriginal people who were living with a serious mental illness shared similar experiences. They spoke of the importance of family as part of their healing, but were saddened and surprised at how mental illness can fracture and distance some family members. Sarah described her sometimes-strained relationship with her siblings:

> “*Sometimes I find it really difficult to explain it to my brothers, you know, that this is the situation. And they say 'Well snap out of it!' Well I wish I could 'snap out of it' [laughs]. You know, I wish I never 'snapped into it' [laughs] ... Mum's the primary carer, all my brothers and sisters, even though they care and they support me and we do social things together and all that sort of stuff, they're still there on the side saying, 'Well snap out of it. Get your life into gear.' And all that sort of stuff.*[19] ”

Gina talked about her family being in denial as they tried to come to terms with her daughter's diagnosis of a serious mental illness:

> “*I think it's different when you're a carer of a family member and in this case, my daughter. In her early thirties or late twenties she started having psychotic episodes. The first thing me and my family did, the ones close to her, was to try and deny that it was happening; we realised this later, what we were doing. But at the time it was like, 'Don't be silly', or 'Why don't you do this, or do that, or try this, or try that', and 'Please, can you take her to live with you', and all this sort of thing.*[19] ”

Families can be complex, as Cathy noted when talking about how her son's mental illness was made more complicated because of his insecurity and confusion about his Aboriginality. Being a sole parent and non-Aboriginal, Cathy felt that she was not able to assist her son with his identity issues. The lack of positive Aboriginal male role models in her son's life exacerbated his situation.

> “*My son was a beautiful child, his Aboriginal father though didn't have much to do with him. He left when he was about 18 months old; I was a single parent. My son had huge identity issues; he identified with his peer group who were sniffers and chronic solvent abusers.* [19] ”

The Impacts of Serious Mental Illness on Families

The children of parents or families where mental illness is present are often invisible, both to service providers and within families. When a serious mental illness impacts on a family there can be serious repercussions, including separation. Joan described the experience of her son's involuntary admission to hospital being witnessed by his children:

> “ *Yeah, you know how children are, they can take things or leave it, but some little things every now and again would come out where you think, 'Oh goodness me'! You know, 'Maybe the kids should have had some counselling', so you had a little talk to them and they would say, 'Nah that's fine, Dad's just this person, that's just Dad'. You know ... they sort of handled it really, really well. Maybe we had put more of our focus on my son and forgot about the children and what they shouldn't, maybe they should have had some counselling. Mainly how the police had to break the door down and their Dad had told them not to open the door, you know, that type of thing just gets to the kids a little bit. And maybe we forgotten about the kids and they should have more or less had some counselling, maybe.*[19] ”

Any approach to mental health intervention needs to address the complexity of family life, underlying issues of comorbidity, drug and alcohol misuse, accommodation, poverty and underlying psychological issues. To just focus on clinical intervention and not the bio-social-psycho-physical aspects is a failure in duty of care.[20]

Being Aboriginal and Living with a Serious Mental Illness

The issue of being Aboriginal and living with a serious mental illness is a critical one. Participants spoke of racism, alienation and social inequalities. As Andrea highlights:

> “ *I mean it is bad enough living with a mental illness but they look at you because you're Aboriginal anyway you're getting the look and its ten times worse if you've got a mental illness. There have been times when I have been in at the mental health service with other Aboriginal young people especially in the adolescent unit and we have felt it.*[19] ”

Many of the comments from participants revealed a deep sense of alienation from the wider community, as Sarah noted:

> “ *I think people think that we, Aboriginal people with a serious mental illness, are all criminals to some degree. The perception is that Aboriginal people with a mental illness commit crimes more than other people.*[19] ”

Their concerns related to the lack of appropriate mental health information, particularly in the event of a mental health crisis.

Living with Mental Illness – But Not Being Heard

The issue of silencing about mental health issues was raised by several of the participants. Silence and shame surrounding mental illness are endemic and entrenched and as a result many of the participants believed that their voices were not being heard.

Aspects of inadequate and culturally unresponsive service provision and support were raised by numerous caregivers. Certain work practices by mental health professionals are used as strategies to cope with burgeoning caseloads which can inadvertently silence the voices of carers and people with a mental illness. Jenny noted that when she tried to access someone to visit her son at home there were excuses given as to why they could not see her son, usually because they were 'too busy':

> “ *I am having trouble with him leaving the house, I need someone to come to my home and do an assessment but the hospital will not visit you in your home. You have to go to; you can't get a psychologist to come and sit at your house to do an interview. You have got to go to them. In my son's position his major problem is leaving the house, getting out of the door. Because all these places say that you need to go to them it makes it impossible.*[19] ”

Lack of Support for Carers

The experiences of alienation and blaming highlight the need for greater awareness raising within the wider community to gain their support and recognition of the difficulties being experienced by caregivers.

Cathy spoke of what she believed were the inconsistent social expectations for someone who was a caregiver for a person living with a serious mental illness:

> “ *I think we live in a society where parents are very much seen as focus of blame or whatever and it's very hard as a carer to not unconsciously take that on, but it's also part of the grieving process as well. So it has been a real struggle for me and probably still is on and off. Because your emotions often are different to what your rational mind is because you know one thing but your emotions can be quite different to that.*[19] ”

The person receiving care is very dependent upon the continued health and wellbeing of the caregiver and this is reflected in Andrea's comments about the lack of support for caregivers:

> “ *There should be more supports for people to be caregivers for people living with a serious mental illness. To help people who are helping those living with a serious mental illness makes sense. For if you are working as a nurse in a ward it can be difficult because being around people with a mental illness is hard, as I tend to go a bit 'loopy' at times. Some people don't even know how to take me… That can be really draining and that's where they [caregivers] need the support. People need to be aware and have an understanding for as I said people are frightened, because they don't know anything about it, and they can get very frightened when they are around people with a mental illness.*[19] ”

The Importance of Aboriginal Workers in Mental Health Services

The issue of alienation was raised by some of the participants. Cheryl noted how she, as a patient, related to the care provided by mental health services:

> “ *Not very good, not very good at all; by not seeing Aboriginal people working in the hospital when I was going through my illness was hard as I needed to see a black face, an Aboriginal face. I needed to be able to sit down with this person and talk to this person about my issues, but they were putting people from other nationalities in front of me instead of an Aboriginal person, a black face.*[19] ”

Cheryl also recalls how she and other local Aboriginal people had previously lobbied successfully for the hospital to employ Aboriginal workers:

> *“Through our local Aboriginal women’s group, there were 15 women, there were grannies, some men, mums and cousins we argued for and now have black faces at the hospital. We now have two Aboriginal workers working at the hospital which is a major improvement particularly from when I was first admitted, that was really frightening.*[19] ”

Hospitals were generally viewed by participants as places of importance, but also as places of last resort. Given the integral part they played in people’s lives, it is disconcerting that for most of the participants their interactions with hospitals were not pleasant experiences. Psychiatric hospitals in general were perceived as unfriendly and scary places. As Andrea notes of her first experience in hospital:

> *“It was very scary; I think I cried for the whole two weeks I was there for the first time.*[19] ”

The use of authority is contentious. If authority is abused, particularly in a hospital context, it can have quite negative consequences. Advocates for the person with a serious mental illness often felt that when they tried to mediate on behalf of the person with a mental illness they were discouraged from doing so by mental health staff. It is important that staff acknowledge and respect the rights of people to advocate on behalf of a family member. Aboriginal mental health workers and liaison staff are needed to effectively play that brokerage role to link families with senior clinicians.

Personal Impact of Caregiving

Due to the physical and emotional costs of being a caregiver, a number of the participants felt a sense of hopelessness for the future, as noted by Cathy:

> *“It’s exhausting, absolutely exhausting, particularly when you have to get up to go to work and having to deal with a pretty tough job. Not knowing what you’re coming home to, thinking I’ve got to get up in the morning so I’ve got to be refreshed and I could get a phone call at one in the morning or two in the morning and have to deal with it. And where to from here then?*[19] ”

Despite the difficulties, there were also examples of hope in Cathy’s story:

> *“I think I’ve been pushed and pushed. I just think that the only thing that I can really draw on as my strength now is just this sense of letting go. Because it’s all out of my control it’s that I can only give so much and then I’ve got to a point now where I have to give him boundaries. I think that mental illness when you’re a carer it pushes you beyond yourself ... You can have times where you can actually see that it’s made you a richer and stronger person. Which it does but it’s not something generally out there in society that most people would say could be the case.*[19] ”

As Ellen noted of her experience of being a caregiver of her grand-daughter living with a serious mental illness, while the issues confronting caregivers can be complex and demanding, certain qualities of strength often emerged during times of crisis:

> *“You have to have strength otherwise you know. It doesn’t matter like every day of our life, every hour, you’ve got to believe that it doesn’t matter whatever you do you’ve got to believe you’re going to come through, and that it will be okay. Every little hurdle regardless, it doesn’t matter how big or small you can still go over it.*[19]
>
> *I suppose we have to have a lot of understanding and lots of love because you got to really care about what you’re doing I think. I was very emotional but I had to put that aside cause I knew that, like, getting emotional wouldn’t help. I mean you do have your moments that are emotional, but I draw strength when you see how much they’re trying. It doesn’t matter, like, every day of our life, every hour, I suppose it will be how you’ve got to believe that it doesn’t matter whatever you do you’ve got to believe that you’re going to come through, that it will be good.*[19] ”

For some of the participants, their Aboriginality and culture were a source of strength, as Cheryl noted:

> *“Our culture we love to bring our culture in especially when our minds start racing and our hearts starts racing. We will go and get our wool and make our headbands and our armbands and our belts. We are concentrating on our colour we’re concentrating on our culture and we know that at the end of the day the things that we make will be handed out, to share as part of our cultural experiences.*[19] ”

As Gina noted, it was the influence of her parents and being Aboriginal that was her source of strength:

> *“I think learning we were brought up as Aboriginal people; that we were Aboriginal. We were also taught the white man’s way as well, as we were taught to cope with the white man’s way because my parents knew that you couldn’t survive by just being Aboriginal it wasn’t going to help us fully. We had to cope with both sides. And that’s what they taught us really.*[19] ”

A BROADER PERSPECTIVE ON CAREGIVING

Defining and Contextualising Caregiving

When care and caregiving have been discussed in the health literature, they have often been influenced by the bio-medical model with a strong focus on the physical rather than the emotional and spiritual needs of an individual.[20] More recently however, with increasing attention to carers and those cared for, and as carers are given more voice, the role and definition of carers has also come under scrutiny.

An example of the more recent scrutiny of the term ‘carer’ is that of Molyneaux et al,[21] based on considerations of the historical and political context of the term ‘carer’, as well as research in various carer-related settings in the United Kingdom. The authors are critical of the term ‘carer’ in that it invariably fails to account for the relationship between carers and those for whom they care. They are also critical of the use of the term in such a way that it may imply burden and polarise two individuals who would otherwise work together. They argue for a relationship-based description of caring and an approach where services focus on the fundamental care needs of the person requiring care. The expectation is that, in this approach, the associated needs of 'carers' may be similarly met. However, the authors do acknowledge the danger of a return to the previous status quo in which care work was invisible and unvalued.

Within the Australian context, the last decade has witnessed an escalation of carer recognition and legislation. The Association of Relatives and Friends of the Mentally Ill (Arafmi) website dedicated to mental health carers, gives testimony to the recent proliferation of formal documents recognising carers. As well as the Commonwealth Carer Recognition Act of 2010,[22] the following Acts and Charters are in place in individual States and Territories:

- Western Australia: *Carers Recognition Act 2004*
- South Australia: *Carers Recognition Act 2005*
- Queensland: *Carers Recognition Act 2008*
- Northern Territory: *Carers Recognition Act 2009*
- New South Wales: *Carers Recognition Act 2010*
- Victoria: *Carers Recognition Act 2012*
- Australian Capital Territory: *ACT Carers Charter*

With some minor variation in wording, the 'carer' in the above is generally 'a person' who provides unpaid care for another who requires help with everyday tasks because of disability, frailty, and/or chronic illness, including mental health. A carer can encompass a diversity of individuals performing a caring role and, though not necessarily elaborated in legislative documents, carer support agencies recognize, encourage and in fact often rely upon, wider family engagement in the caregiving situation.

Edwards et al,[23] in an Australian Institute of Family Studies report on the impact on families of people with a disability, drew attention to the need to contextualise caring:

> *To understand the experiences of carers of people with disability, the broader context of the family and social environment in which the care takes place needs to be considered. These contextual factors include family relationships, marital relationships and support networks.*[23(p30)]

Although mental health carers share commonalities with other carer groups around having to deal with daily life issues of family, finances and maintaining their own wellbeing, they are recognised as unique because of the additional stressors they have to face in their caring role. The nature of mental illness itself—with predominantly behavioural symptoms as opposed to clear physical ones, societal perception of the illness and the structure and delivery of mental health services—make mental health carer positions different and unique to other carer groups.[24]

In the context of Aboriginal mental health caregiving, I propose a more realistic and comprehensive definition:

> *Aboriginal caregiving should be viewed as a whole-of-life experience and seen in the context of an individual nested within their family, and their community. Caregiving includes all of the social, emotional and cultural support that enhances the wellbeing of the individual, family and the community where a member has a disability.*[18(p204)]

The stories described in the current study strongly affirm the need to broaden the context within which caring is considered. They show that the experience of caregiving within an Aboriginal context is often a seamless activity involving individuals, families and communities.[18] As such, the Aboriginal experience of caregiving has much to inform the broader discussion around the term 'carer'.

An Aboriginal Framework of Caregiving

This section explores an Aboriginal framework of caregiving, developed from the findings of my study, to reflect, acknowledge, and take account of the lived experiences of Aboriginal people as caregivers for those living with a mental illness. The Framework ensures that these are framed in the context of their historical, social, cultural and political realities. The historical context in Australia includes the impacts of dispossession and forced removal of Aboriginal and Torres Strait Islander peoples from their land and the state-sanctioned programs of separation of children from their families as described in Chapter 1 (Dudgeon and colleagues) and Chapter 17 (Atkinson and colleagues).

In line with the recent focus on the caregiving context, its dimensions and how it shapes the process and outcomes of family care, this Aboriginal framework firmly locates care within the family rather than a single individual and, in turn, the family is embedded within a larger cultural, community and social context. Aboriginal people understand the importance of care in providing stability and as such have prioritised caregiving in their families and communities. The practice of caregiving from an Aboriginal perspective can best be understood as an activity applied in the everyday setting and including *caring about, taking care of, providing care* and *receiving care*.

Caring about

Caring about is the recognition that there is a need to provide a person with care which has both communal and individual qualities. Within an Aboriginal context, 'caring about' applies to the person, and to the person in the context of their family, their community and the wider environment. In order to be effective, mental health providers and others social services need to understand and take account of the complexities that exist within Aboriginal families and communities as well as the unique issues confronting care givers in families living with a serious mental illness.

Taking care of

Taking care of involves the commitment and responsibility in responding to the person receiving care needs. The concept of 'taking care of' is more than just recognising that there is a need; it involves the commitment to being active in responding to and resolving those needs. Being responsible is central to the activity of taking care of. This has wider implications, because responsibility is integral to the continual health and welfare of Aboriginal society.[25] The recognition and practice of culture are central to the health and wellbeing of Aboriginal communities, and inherent in these cultural practices is the action of responsibility fortaking care of family, community and country.[25,26]

Providing care

Providing care involves the responsibility of acting on behalf of those in need of care. It requires the total commitment to the task of caregiving. It is common for Aboriginal families to have three or more generations within a household, and providing care across these generations is accepted as the norm, despite the difficulties it may create due to the lack of resources.[6] Recognition of these circumstances may assist practitioners in asking the right questions and assisting families to plan how to support someone with a mental illness and at the same time recognise the potential impacts for the children and other family members and carers.

Receiving care

Receiving care assumes that the person receiving care will be responsive to the caregiving that is being provided. Care recipients in the study acknowledged the difficulties involved in the caregiving activity; they expressed their concern at the lack of services and support for Aboriginal caregivers. Given that the person receiving care is very dependent upon the continued health and wellbeing of the caregiver, it is really important that mental health practitioners (and other service providers) attend to the health and wellbeing needs of the caregiver and encourage them to link in with appropriate networks and carers services that are available in the community.

CONCLUSION

This chapter has shared stories of the experiences of Aboriginal families as care givers and care receivers and outlined an Aboriginal approach to caregiving to assist mental health service providers and practitioners to develop more culturally responsive services, policies, practices and principles. It has argued the need for mental health practitioners to adopt a culturally responsive and respectful process when working with Aboriginal families who are living with a serious mental health illness. The basic qualities for all mental health service workers are a commitment to relationships and continuity of care, both of which derive from cultural life tools.

The stories of Aboriginal families recounted here affirm that caregiving is culturally a highly valued activity. Importantly, they highlight the need for service providers and mental health practitioners to recognise the unique contributions these caregivers make to supporting people living with mental illness, and to engage with Aboriginal individuals, families and community in a more respectful manner.

Recognising the high value and unique contribution of carers requires that service providers:

- incorporate partnership, collaboration and transparency in their practices;
- engage in a more meaningful way; and
- acknowledge and recognise that carers are not separate from but an integral part of the community.

In essence the stories in this chapter are a reminder to all of us about the importance of being there and being human in our everyday lives and in our work.

REFLECTIVE EXERCISES

1. Review the current protocols and practices in your agency for working with Aboriginal families. How do these protocols and practices fit with Aboriginal and Torres Strait Islander principles and values? If they don't, how can you change the protocols so that they do reflect Indigenous principles and values?
2. How can you and your agency adopt a more proactive position when working with Aboriginal people and communities in your local area?
3. How can your agency's policies and practices be adapted so that they remove the structures that privilege and support colonialist practices that exclude and disenfranchise Aboriginal and Torres Strait Islander peoples?
4. Review and identify current policies and practices that 'pathologise' Aboriginal people, in particular, through the negative representations in reports and publications. If present, how can you change policy and practices in your agency so that they do not misrepresent and reinforce negativity?
5. Review the current protocols and practices in your agency that might encourage discrimination and racism in the lives of Aboriginal people. If present, how can you change your agency's protocols and practices so that it adopts and models an anti-racism stance within and outside the agency?

6. Examine how your agency's policies and practices exclude and marginalise Aboriginal people. If present, how will you change your agency's policies and practices so that they are more inclusive, open and empowering?

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